

**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Teleconference
February 22, 2005**

Presentation:

EHDI and Minority Populations

TO: Ad Hoc Group for EHDI
FROM: Jamie M. Elliott
SUBJECT: Conference call information and transcript.
DATE: This teleconference was held from 3:00 to 4:00 pm EST on Tuesday, February 22, 2005.

Dr. Steinberg coauthored the report, "A Look at the Decisions Hispanic Families Make After the Identification of Deafness," which can be accessed at <http://clerccenter2.gallaudet.edu/KidsWorld/DeafNet/e-docs/HispFam/index.html>

Agenda

- I. Welcome – Jamie Elliott, CDC EHDI Team**
- II. Claudia Ortiz, "EHDI data and minority populations"**
- III. Dr. Annie Steinberg, "Decisions Hispanic families make after the identification of deafness"**
- IV. Dr. Lori Taylor, "Providing care to Southeast Asian families"**
- V. Claudia Ortiz, "Strategies to increase follow-up among minorities"**
- VI. Questions and Answers**

Topic Abstract

As the number of minority individuals in the United States increases, so does the number of babies being born to minority women. Factors such as poverty, low education, language barriers, and lack of health insurance among others, may leave children born from minority mothers at risk for developing birth defects and developmental disabilities such as hearing loss. EHDI has been playing an essential role identifying minority babies born with hearing loss before one month of age. However, the cultural, language, and sociodemographic barriers that minority families usually have to face can be difficult to overcome when looking for appropriate follow-up and early intervention services. Utilizing strategies to reach minorities can potentially help to reduce the loss to follow-up among these populations.

EHDI and Minority Populations

Edited Transcript – version 3

Jamie Elliott: We're going to wait just a couple more minutes and then we'll get started here.

For those who are on the line I want to let you know if you haven't already you can download the power point presentations from our presenters today. The address that you can find them at is <http://www.infanthearing.org/checkpoint/cdc>. You will be prompted for a code; just enter "cdc" and enter "cdc" as the login also.

Let's go ahead and get started. Good afternoon, this is Jamie Elliott from CDC, and I would like to welcome you to the Teleconference. I'd like to thank our speakers and all of you for calling in.

Participant: I want to mention I'm hearing some music.

Jamie Elliott: Yes-- That probably means someone has us on hold. When they come back to the call, that music should disappear. Is everybody hearing the music?

Participants: Yes, Yes.

Jamie Elliott: Can you still hear me speaking?

Participants: Yes. Yes. Yes.

Jamie Elliott: Hopefully whoever has us on hold will join us shortly and the music will go away. Which reminds me to ask you, please do not put us on hold. Just mute your phone if you're not going to be speaking, and if you need to hang up to leave the call, please just hang up completely and call back into the call number when you are ready to rejoin. When you leave your phone on hold we all get background music.

This afternoon we have three speakers who will be addressing the topic, *EHDI and Minority Populations*. Our first speaker, Claudia Ortiz, will begin by providing an overview of EHDI data in minority populations. She will also conclude the call by giving strategies in reaching minority populations. Claudia has a Masters degree in Public Health and works with us here at CDC. She's adapting many of our resources both linguistically and culturally for Hispanic populations.

Dr. Annie Steinberg is an Associate Professor of Psychology and Pediatrics at the University of Pennsylvania School of Medicine, and her work is based out of the Behavioral Health Center of the Children's Hospital of Philadelphia. She has conducted research to examine access to healthcare for adults and children who are deaf and has

directed a child abuse prevention program and family preservation services for families who are deaf. Dr. Steinberg has worked in hospital based clinic programs as well as school based mental health since 1985, establishing two clinics in Harlem high schools and in Philadelphia. She's the author of the website www.raisingdeafkids.org, which is a website that specifically aims to outreach into underserved community. It has over 250 topic pages, more than 100 of which have been translated into Spanish. Today Dr. Steinberg will be speaking to us about a report she co-authored entitled, "Decisions Hispanic families make after the identification of deafness."

Our third speaker, Dr. Lori Taylor, is an Assistant Clinical Professor with the Department of Pediatrics at the University of California, San Diego. She has worked as a physician for the Children's Hospital, San Diego and as a medical consultant for UCSC. She presented with a colleague, Dr. Linda Jacobo, on *Cultural Competence in the Practice of Medicine* at the American Academy of Pediatrics conference last fall. Dr. Taylor will address the issue of providing care to Southeast Asian families today.

As I mentioned earlier, some of our speakers will be using power point presentations to accompany their talks. These power point presentations can be downloaded at <http://www.infanthearing.org/checkpoint/cdc/>. Today's teleconference is being recorded and a transcript will be available on the website in two or three weeks. Again please make sure your phones are on mute and do not put your phone on hold. Instead, please hang up and call back in if you need to leave the call.

With that I'll turn it over to Claudia to begin our presentations for the day.
Thanks for joining us.

Claudia Ortiz: Hello, everybody. Can you hear me well?

Participants: Yes.

Claudia Ortiz: Okay. Thank you so much for being here today and listening to this teleconference. And thanks to Jamie, Dr. Steinberg, and Dr. Taylor for being here and for being our speakers.

I made two power point presentations that I hope you were able to download. The first one is called, "EHDI and Minority Populations". With this presentation, I would like to give you some background about what is happening with the minorities in this country. If you look at the second slide it will show you how the minority population is growing in this country. Minorities right now are more than 30% of the U.S. population. However, the number of babies born to minority mothers accounted for more than 40% of the total U.S. births in 2002. For instance, if you look at the third slide, you can see the fertility rate among Hispanic women was approximately 40% higher than the black women and more than 45% higher than those for women in other racial and ethnic groups. As the number of babies being born to minority women in the U.S. increases, so does the probability of having more minority children with birth defects and developmental disabilities, including hearing loss.

Look at the fourth slide. Almost half of the students with hearing loss who received special services in this country in 2002 were from minority groups. Severe to profound sensorineural hearing loss has been found in higher proportions of children with minority and/or lower socioeconomic status. On this fifth slide, I would like you to think about the possible causes for this situation. Although it can be difficult to determine the causes of birth defects factors such as poverty, low education, language barriers, and lack of health insurance among others may leave children born from minority mothers vulnerable for developing birth defects and developmental disabilities.

Slide six explains the essential role that EHDI programs have been playing identifying children born with hearing loss. However, in the year 2002, only approximately half of the children screening positive were reported to have received recommended follow-up services. Some of the factors predicting non-compliance with follow-up recommendations, as we can see in slide number 7, are: Non-white race (including African Americans, Hispanics, Asians and Pacific Islanders), no insurance (that is the case for Hispanic and Native American populations), young maternal age (the teenage pregnancy rate continue to be higher for the Hispanic and black population), having more than two children at home (this is common, for example, among Mexican families), and late onset of prenatal care, (this is closely related to lack of health insurance and low education). All of these issues need to be considered when implementing EHDI programs.

Now Dr. Steinberg is going to talk about the “Decision-making process for Hispanic families after the identification of deafness.”

Dr. Steinberg: This teleconference is a test of how well we're able to mute some auditory input. Unfortunately, just as I said that I think the music went off. Is that right? Are we not hearing the music now?

Participant: No, we still hear it.

Dr. Annie Steinberg: Well, maybe because I'm talking they're kind enough to mute it for me. Let me tell you a little bit about work that we've done. The diagnosis of a chronic condition in an infant or a child can have a profound impact on the family, and in the case of deafness, that is true as well. One factor obviously influencing the response by a family to a child's disability is the family's cultural background and cultural elements such as language, family structure, gender roles, beliefs about health and hearing as well as stress-all play significant roles in the family's decision about their child's rehabilitation and treatment and any kind of intervention at all.

As Claudia mentioned individuals of Hispanic descent are the largest minority group in the United States, accounting for 12.5% of the total population and rapidly growing. And while it's growing, it is not growing as a homogeneous community. This is a heterogeneous community, and we work so hard to learn more about in our work and research, understanding parental decision-making in Hispanic communities.

And I use the word plural, communities, because immigrants derive their cultural identity from Mexico, Puerto Rico, Cuba, Central, and South America. While they share certain cultural traits such as the Spanish language as well as an emphasis on the importance of family, there are many unique cultural traditions for each particular group and subgroups. The Hispanic community in America is diverse.

Many people sacrifice so much to come to and remain in the United States and do so after they find out they have a child with a special need or disability because the belief is that the services will be better here, and most of the time they are better here. Many of the families we work with risk deportation to remain in the United States. Some have a tremendous amount of formal education, have professional post-doctoral degrees at home and certification in the United States is not possible. But for others, there's little or no formal education so there's diversity in that, too.

The extended family we mention, the family being so important to this group, can play a very, very significant role as is traditional to the culture which can be helpful both in support and child care and financial assistance. It can also be a hindrance in the areas of opinionated relatives sustaining old world beliefs, promoting the notion of the deaf child as a disabled and incompetent child as they age into adolescence and adulthood. So unfortunately, there are many, many complex factors which make the disability just one of many isolating variables. A parent who comes to this country to get services for the child may also be at an additional deficit. Many of the families we interviewed expressed difficulty dealing with their larger communities and stigmatization and lack of understanding about their child's deafness and deafness in general.

Most of the families we interviewed identified problems communicating with their children, although some families insisted they understand their children and their children understand them regardless of the language they spoke, the speed with which they spoke, and so on. But the families had additional stress as a result of separation from their family and from community supports, and they may, in fact, have additional difficulty in coping with and navigating through the decision-making process for their deaf children.

The study that I was asked to talk about today, to inform the rest of the folks listening, involved four distinct geographical areas in the United States. We interviewed families in Pennsylvania, Texas, Florida, and California so that we would have a good variety of cultural backgrounds and experiences as well. And in fact, there was variability. For example, in Florida, the region in which we interviewed parents reported more access to bicultural service providers and interpreters than in any of the other three sites.

I won't be going into any of the methodology. You can find that in the website and the article itself. If, anybody wants any more information they can contact me by e-mail through the website (www.raisingdeafkids.org). I'll be happy to respond, but I will tell you some of our findings now, as well as some of the implications for practice.

We were particularly interested in decision-making, and we knew that the decision-making process for children with hearing loss is a complex one, affected by information and

resource availability, the quality of the information that's given by professionals, the parents' ability to get information, the preferences and values of the parents and their decision-making style as well as their beliefs about the cause of and consequences of deafness. But in many of the cases there were huge barriers that prevented the parents from participating fully in the decision-making process.

Let me explain a little bit more about that. More than half the families we interviewed reported experiencing language difficulties that interfered with their acquisition of information. Language differences presented barriers in some situations, but in other situations some Spanish speaking professionals or interpreters through their own English abilities mitigated these problems. But when this occurs it is a very, very potent and long lasting experience. One mother described being “imprisoned” or trapped by the language. She noted that in a foreign language the words don't come out, but if she were speaking in Spanish, she would have been free-- literally free to ask the questions that she wanted to ask. Otherwise, she was basically just paralyzed, and this was a woman who could speak English fairly well.

So the ability to speak and ask questions, pose questions directly to the audiologist and the interventionists is key for some families. Others complained about the nature of the interpreting and how in spoken language there was a difference that could not be overcome. “We have the same culture, but we don't have the same language,” complained an interpreter from Mexico about a Puerto Rican family. A number of mothers complained about the information that was interpreted by school staff into Spanish. They said, “I prefer it in English because the Spanish they give me, they really kill it. I really feel bad, but I tell them, ‘send it to me in English because you have a problem with translations, and they kill the Spanish!’” Language is a very, very central issue for many of the families.

Regardless of what we as professionals may say and what parents may politely listen to and nod their heads to, families we interviewed want their children—hope that their children will be trilingual in English, Spanish and Sign language. While we had a few families that preferred English or Sign language above all, most really desperately yearned for their children to know both (particularly English and Spanish) because they want their children to know their culture; they want their children to be able to converse with family members. And that becomes very, very delicate and important topic around which professionals may improve in terms of cultural and linguistic sensitivity.

One of the things we found was that the families we interviewed did not feel that they were given many options. That may have been a reflection of few offered choices, or that may have been the perception of few options. We know in our own community that many times, parents who speak Spanish are not told about cochlear implantation because they're felt to be less likely to have a positive outcome if the parents do not speak English. And that's a very, very important area for us to explore in the future.

A majority of the families we interviewed spontaneously raised the issue of their religious beliefs and faith influencing their decision-making process and their whole life with their child. That, again, is not an area about which many early intervention specialists and

audiologists are given a lot of training. So that's another critical gap or barrier in communicating with some of our families.

The information they've been given has been largely unavailable in Spanish or incomplete. And while English speaking parents can obtain materials from numerous sources, it appears Hispanic parents have far fewer resources at their disposal.

Just to wrap up with a couple of comments about practice, in our interviews and our clinical work, we have found that cultural competence in working with this community is served well by the presence of a cultural intermediary. We hired a lay minister to go to the families' homes with us and he would literally call the family from outside to let them know that we had arrived. Otherwise they would not always respond to the knock on the door. Then he'd come into the house and sit and have a cup of coffee with us. Once he saw that we were setting up our video cameras and audio tape players and that everybody was settling in for the interview, he'd excuse himself to go back to work. We found that was a very helpful both in connecting with the families for the interviews and connecting in a positive and meaningful way during the process of the interviews. And it went a long way in establishing trust within the first five to ten minutes, just his very presence and endorsement of our being there.

In regions with access to bilingual professionals, parents have more of a sense of empowerment. We've found out that working hard to understand and respect the families and the role of religion and faith, their values and beliefs, and honoring the family structure is critical, and this is more than just the words that we use. This relates to some of the nonverbal emotional displays we as professionals have, sometimes unconsciously, but they are carefully monitored and perceived. The perception of being respected is critical to any work with these families. That's probably true for all families, but in this community, we've found that's very, very important, this incorporates not feeling as if they're being rushed.

That doesn't necessarily mean more time-- just attitudinally, for example, that three minute cup of coffee before we started the interview was very, very important in establishing respect for the home, the family structure and cultural traditions.

Also, we found that recognizing all that the family does for their child and their accomplishments in their care of their child, and linking them with other similarly competent parents of Hispanic background is a very, very helpful gift back to the family. It recognizes their abilities to support one another and ultimately become teachers for future parents.

Finally, I wanted to mention that many of our families have to endure the negative stigma associated with deafness and culturally may believe that their child is something to be sad about, to pity, will need care for the rest of their life, and so on. So it is critical, really, to address the 'can-do', the positive opportunities for their child.

And that we have tried to address in one of our pages that's specifically written in Spanish. It's entitled, "¿y porque non? y tu nino puedes tambien (and your deaf child can as well and

why not?)" You can find that on the website. In English we have a rough translation, "your child can succeed." But, what we call the 'el sindroma pobrecito' is not limited to the Latino community. It is often rooted in religious beliefs and relates to *the will of god, this is what has come to my life and this is whatever god wants* mindset. *It's my duty to care for this child throughout his life or her life*, facilitates dependency and does not foster autonomy or transition to adulthood, so that the beginning in working with a very young child is the time to begin promoting the notion of a competent deaf child and adult, right from birth and identification after birth. That's all that I'm going to say., . I'll be happy to take questions if that's a part of this teleconference.

Jamie Elliott: Thank you, Dr. Steinberg. That was a very interesting presentation. We're going to hold off on questions until the end, so if you have questions please hold but we can continue with Dr. Taylor's portion of the Teleconference.

Dr. Lori Taylor: Okay. Well, we're going to switch gears a little bit. Thanks, Dr. Steinberg.

We've been hearing a lot about the Latino population, probably the largest and most well studied minority group in the United States. And what I'm going to do is switch gears a little bit and talk about a minority population that's not quite as large in number as the Latino population, but that also is a population with some very discrete health related beliefs and practices, and a population that's growing rapidly as well. Similar to the Latino population, it's a very heterogeneous population, and we'll talk about that a little bit in a moment.

I developed my interest here by spending much of my time in a community clinic here in San Diego with a very large patient population. And my interest in the area of cultural competence grew as I began to realize there was a very specific skill set needed to effectively work with this population. Most of my material will cover health beliefs and practices that aren't specific to the EHDI community but hopefully will be useful for anyone working on a daily basis with people from the Southeast Asian region.

The first thing I'd like to do is make a disclaimer once again that the Southeast Asian cultures are very diverse, and not all Southeast Asian patients are going to be the same. And whether a particular patient ascribes to any of the described beliefs of the group will depend on many factors including age, level of acculturation, socioeconomic status, level of literacy, language spoken to name just a few. However, I do feel there are enough similarities in some of the health related beliefs and practices to present this group as a whole. What I'd really like to do first is share with you all a model that I use to try to eliminate the potential for the stereotyping when talking about specific health related beliefs and practices of groups. This is a model that was developed by Lee Pachter which he calls the *awareness- assessment- negotiation model*.

The first part calls for *awareness*. It calls for a specific provider to become aware of commonly held beliefs and practices in the communities in which we work. So clearly, a

service provider who works with the Native American population will know a lot more about their traditional beliefs and home remedies and practices than the average provider. So it behooves us to really get to know our patients and our clients, and how we do that can be through very different avenues. We can just have dialogues-- open dialogues-- with our patients, and they can be our own best teachers. There's also a wealth of information in the medical anthropology literature about health related beliefs and practices of various cultural groups. And there's a growing body of web-based resources as well, that will help one to become familiar with the population with which you're working.

The second part of the model is really the part to kind of eliminate the stereotyping or bias that may be inherent here. That is the *assessment*, to assess whether the specific client that you are dealing with or the specific family does relate to the beliefs and practices of the whole and under what circumstances. I find that the best way to address this on a day-to-day situation is with very open-ended, non-threatening questions, much like the way many of us in medicine are taught to work with teenagers. When we're asking a teenager about sensitive topics such as sex or drugs, we'll say, "Many high school students are starting to experiment with certain substances. Is this something that you've been doing or any of your friends have been doing?" Much in the same way, we'll say, "Many of my patients [perhaps we're talking to a Latino family about a belief in the evil eye, as many of my patients have concern about this] are concerned about the evil eye. Is this something that you're worried about with your child?" This puts it in a non-threatening context, and allows the client to know you're interested in their beliefs, and you have some background of understanding. It puts the ball in their court as far as letting you know where their beliefs lie. Some Latino patients don't believe in the evil eye. They think it's pure nonsense. So it behooves you to find out where your client or family falls in that spectrum.

The last part of the model calls for *negotiation*. Attempting to find ways to integrate patient held beliefs and practices with our own biomedical treatment and health education and health maintenance plans. Many times this will involve encouraging the use of neutral either potentially helpful traditional remedies or traditional approaches to a problem, while discouraging those approaches or those remedies that could be potentially harmful and trying to strike a balance between the family's own beliefs and preferences and our biomedical plan of action that we may have. One example that I like to use here is for this *awareness-assessment-negotiation model*, is the concept that I brought up before of the evil eye. The reason why I use this example is many people are familiar with it. In the Latino population, there's a belief that either a strong look or a stare by another person can either intentionally or unintentionally be harmful to a child by giving them the "evil eye". Many Latino infants will wear protective charms around their wrists to protect them against evil eye. For many practitioners, especially pediatricians, our main concern with this dangling object hanging around a child's wrist is the possibility of choking. If you're not familiar with these health related beliefs and not practicing in a very culturally effective way you may just say, "That has to go; it's a choking hazard." And, if done very abruptly without regard for the deeper meaning that it carries to the family, that can really alienate this particular family from you. So a provider who works with many Latino families would, number one, be aware of the concept of evil eye and about the manners in which parents try to protect their children. Then, when they see this particular child, they may assess

whether this family indeed believes in this. You say, “Many of my patients wear these charms as protection. Is this something you're concerned about?” If the family says, “Well, yes. This is given to him by his grandmother as protection,” then you have to enter into the negotiation phase where you say: “Well, my concern as a pediatrician, is that this may pose a choking hazard. Is there some other way we might be able to protect him from this? Perhaps a safer way?” This allows you to talk about it in a very non-threatening way. That's just one example of how that would be a much better approach than simply telling the parent, “that's a choking hazard, and it needs to come off”.

To switch gears and talk specifically about our population of interest, I'll be talking about patients that hail from Southeast Asia, and I'm primarily talking about people from the countries of Vietnam, Cambodia and Laos with specific attention to the Hmong culture. They live in the mountainous areas of Laos. They're sometimes referred to as “the hill people”. They're primarily agrarian cultures subsisting on farming. Some have termed them to be a primitive culture because there's a lack of written language traditionally in the culture. They have a written language that was created in the earlier part of the 20th century so this is something that's relatively new and much of the folk lore and tradition is passed down verbally. As we mentioned before this group is extremely heterogeneous and our Southeast Asian refugees range from highly educated multilingual former cabinet ministers to non-literate hill tribe people who practice agriculture primarily. It's a very diverse group, but the first thing that I thought I'd share is some of the cultural norms and values that are sometimes expected in interpersonal reactions -- interactions on a day-to-day basis.

The head is the sacred part of the body so to walk up to a child and pat the child on the head or touch their head or hair casually may not be viewed favorably by the parents. The feet, in converse, are also considered to be the lowliest parts of the body. So to point at a toe or an open toed shoe or the sole of a foot at another person can be considered to be an insulting sort of gesture. One that is very important and that I have really learned a lot from in the day-to-day practices is that aversion of gaze demonstrates respect when a Southeast Asian client or patient is dealing with someone they view to be in a position of authority. Before I was aware of this belief or this phenomenon I would spend much time trying to catch the parents' eye, the children in my practice because I felt they either weren't attending to our discussion, they weren't interested, that they didn't understand, or they didn't agree with me. And now I do recognize that their aversion of gaze to me is actually a demonstration of their perceived respect for my position as a physician, and I don't automatically assume that that is showing a lack of attention because in our western culture we associate eye contact with honesty and attention. That's not necessarily so in other cultures especially the Southeast Asian culture.

Another fact is that enthusiastic admiration of babies is discouraged. It has similarities to the evil eye concept in the Latino population, but a little bit more of a spiritual one. It's thought if the baby is praised effusively then the spirits, who are sort of natural guardians of a person's health and welfare, will hear this praise and steal the soul of this baby. I've asked several of my very acculturated sort of young 20s parents about this belief, and it is a very prevalent belief that mothers and grandmothers talk about in the home-- a baby is not

to be overly fussed over and admired. In the native country of Laos, babies are dressed in colorful festive hats to disguise them from the spirits who are looking down from above as flowers so that the spirits won't be tempted to come steal this baby.

Another gesture that can be a problem is beckoning with an upturned finger or snapping of the fingers to get the attention of a child. To have them look at us or attend to something that can be considered to be offensive or provocative gesture to some of the clients.

How to interact with Southeast Asian patients: I don't avoid the head in infants. I need to examine the head and the ears and the eyes, but I proceed slowly. I don't do things casually and I explain what I'm doing as I go. I will sometimes, if I'm getting a feeling things aren't going quite right, look at my body posture to be sure I'm not pointing the sole of my foot at somebody or inadvertently offending somebody by my body posture, and I do recognize that aversion of gaze is meant as a sign of respect for me. I'll just ask direct questions if I feel I need to clarify things. I may ask patients to repeat instructions back to me which is always a good idea even when you speak the same language. A little bit of politeness and formality is expected in interpersonal relations and not the enthusiastic admiration of babies we may do in other cultures.

Moving on to concepts of disease and concepts of health and wellness, there are three named categories in which many of the traditional illnesses are felt to fall: The metaphysician call, the naturalistic, and the super natural. By metaphysical diseases, we're talking about diseases felt to result from an imbalance in hot and cold. Sometimes this is actually a literal translation from a child was outside on a hot day and went inside into a cold building and began to cough. The usual interpretation much of the time it refers to a more conceptual description of the hot and cold imbalance. There are certain illnesses, certain parts of the body, and certain life experiences that are felt to have either hot or cold properties, hot being energizing and cold being calming. And I've listed on the slides, just an example, several illnesses that are felt to fall in either the hot or cold category. For example, childbirth and the period of postpartum recovery are felt to be cold illnesses. The reason for this is because during childbirth, much blood is lost and blood is a hot, or an energizing force within the body. So then you have an imbalance, the body is left in a cold state, and a mother who's recovering from childbirth is felt to be in a sort of cold state or suffering from a cold illness. So the treatment of hot and cold illnesses as we'll see on the slides is mostly from the principle of opposition.

So people in a cold state are treated with hot or energizing treatments that mostly consist of certain foods: meats, wines, foods that are spicy, greasy or salty. In the Laotian culture, a practice called "mother roasting" is performed where a mother is kept during the postpartum period for a variable amount of time (from 8 to about 30 days) in a bed in which other people assist her in caring for the infant. She is kept in bed with a fire lit underneath the bed so that she will be sweating and flushed at all times. This is felt to restore her vital force. There is a hospital in Northern California that was having trouble recruiting Cambodian and Laotian woman into the perinatal program. It wasn't until they employed a bicultural and bilingual health worker that they discovered the main objection to actually having some of the high risk deliveries in the hospital and they would not be able to

practice mother roasting. The hospital did a little negotiating and agreed to provide space heaters that the patients could use under the beds. This was acceptable and resulted in an increase in utilization and hopefully improved outcomes for patients as well.

So moving on, naturalistic causes of illness are felt to be caused by “winds”. Sometimes that refers to actual changes in weather, but other times it refers to more nebulous changes in the environmental energy flow. Illnesses that are caused by having the winds or the environmental energies of the world enter the body examples of those are rheumatism, headache and some respiratory diseases. There are certain times when an individual is felt to be more susceptible to diseases that are caused by wind; the newborn period is one of them. And that is an explanation for why many babies, even in 80-90 degree weather, will arrive bundled, and families will be resistant to unbundling them to perform whatever necessary procedures we need to do, whether it's just to take a look at the infant or take a temperature or perform any other assessment. This doesn't necessarily have much to do with the infant actually feeling cold, but is about protecting that infant from changes in the environmental energy. At time of surgery, surgery is also viewed as potentially opening the body and having opportunity for winds to enter the body and to cause a person to fall ill. So many patients will be reluctant to do elective surgeries for that reason.

Treatment of illnesses caused by winds, many people are familiar with the treatment of coining or cao gio. When a coin or any other substance like a spoon or an egg or a person's fingers are roughly rubbed over the surface of the skin where the point is actually to produce the bruise-like appearance that you'll see in this photograph on the slide. Any time you bring the blood to the surface of the skin, that is felt to allow the wind, or the bad humor, to be eliminated. This is not considered to be a form of child abuse. It's done with the intention of relieving the child of fever or other illness. Most people will tell you that it's not a very painful procedure, and many people actually report feeling better afterwards. This is a practice to be aware of if you're working with this population.

Super natural causes of illness include illnesses that are caused by a person having either a failure to honor their own ancestors or a person suffering fright, grief or unkind words that may injure their own spirit. Again, cutting the body, such as in surgery, or withdrawing blood is felt to possibly be able to lead to soul loss as well. There are preventive issues that arise. Similar to our Latino babies, many Southeast Asian babies will wear charms or simply have yarn tied around their wrist to lock the soul to the body to protect this baby from soul loss. What appears to be simple adornment on these babies may actually carry a much deeper spiritual and protective meaning for the family. As far as treatment of illnesses that are caused by spiritual factors, many families will rely on shamans, which are individuals thought to possess specific powers in being able to communicate with both ancestors and with spirits, and ceremonies will be performed in which a shaman will offer a sacrifice of either food, money or animals in return for the safeguarding of the patient's spirit. Even if it sounds far out there to some of us who don't practice these beliefs, many of our patients use these before coming to seek western medical care for a variety of their ailments, and we won't know about it. They're too polite to tell us about it because it would be disrespectful to let them know-- to let us know that. So, many of our patients will not tell us this unless we ask them about it.

Just a few specific beliefs about hearing loss-- You'll find many similarities among cultures here. As far as where hearing loss may fall in our spectrum of diseases, it is most likely to be by traditional means to be viewed as being due either to fate or due to spiritual factors. And it's possible that deaf or hard-of-hearing children may be thought of as always being dependent on their families, similar to the syndrome that was described by Dr. Steinberg. Similarly, they may be some stigma associated with this physical disability, may be viewed as being shameful for the family. So these are just a few of the barriers that many of you may need to overcome when working with this population.

There are some specific beliefs that many of our Southeast Asian clients may hold about our Western medicine and our biomedical interventions. One of them is that western medicines or interventions will affect their cure rapidly. We need to be very clear in our expectations whether we're prescribing a medication or doing hearing amplification or any kind of intervention, we'll need to be very clear about our expectations for the family so that the family doesn't give up hope prematurely and abandon the treatment. Another common belief is that medicines are too strong for the small Asian body size, and some health nurses will tell you stories of visits to homes where pills are cut in half and bottles are half empty because of this concern. So again we need to be clear as to how we're determining our treatments. Another belief is that x rays are curative or they're dangerous. There's some small truth in that last comment, but there seems to be an overwhelming concern of x-rays out of proportion to the actual risk. There may be a belief that x-rays are curative, and diagnostic tests may be viewed as something therapeutic on the part of the patient, so we need to be clear about what the purpose is. Whether we're ordering a cat scan or a chest x-ray, we need to tell our patients that this will not make you feel better, but it will help us determine what the next step is in your treatment. And then there is a very concrete concern about blood leaving the body not being replaced. That is one that may cause some parents to balk at any needed blood tests for their children, because there's the fear that this blood will not be replaced. There is an opportunity there for negotiation if we understand that this may be a potential fear that a family has when they appear to be resisting any laboratory tests.

I want to end with this recommended reading you'll see here in your slide. If any of you work with any Southeast Asian families, the book, [The Spirit Catches You and You Fall Down](#), by Anne Fadiman is a fantastic exploration of a culture clash between a very traditional Hmong or Southeast Asian family who has a child with epilepsy and the biomedical world. It's really an eye opener for anyone who works with anyone from a culture that is different from their own and I will turn it back over to Claudia.

Claudia Ortiz: Thank you so much, Dr. Taylor. In this second presentation called "EHDI strategies to increase Follow-up among minorities," I want to give you some tips useful to reach minority populations in your state. The first strategy is to develop culturally sensitive materials in different languages and for particular populations. Many states have materials in different languages, such as Spanish, but oftentimes these tools are straight translations from English. Minorities should be included in the design and implementation

of their own educational materials through different means, such as focus groups, and also people familiar with the language and the culture of the intended minority population should be included in the development and translation of the materials. Materials should also be written for approximately a 4th to 6th grade level. They should use appropriate words, phrases, and pictures familiar to the given subgroup and a format that sparks the group's interest. The materials must also be tested with members of the target population to assure that they are appropriate and effective.

The second strategy is to offer additional resources where minorities can find more information. The majority of the materials that are translated to other languages don't include telephone numbers where non-English speaking parents can call and ask for more information. Most of the numbers are available just for English speakers. If your state program has difficulty providing an operator who speaks the language of the minority, there are some more options that can be used. For example, create a phone line with a recording that is checked by someone who speaks the given language and can call back with the requested information. Also add information about EHDI to health department numbers that already have information in other languages, and provide minority families with resources where they can find information or assistance in their native language.

The third strategy is to disseminate EHDI message within minorities. Identify and engage key community partners, such as minority families of children with hearing loss, and healthcare professionals and institutions serving minorities can help to disseminate EHDI message. Broadcasting information in different languages and taking advantage of the media sources available such as Spanish TV, radio, and newspapers in different languages can also be a good strategy to reach minorities. Contacting the local newspaper or TV station can be a good way to start exploring this possibility.

The fourth strategy is to have people who can speak the language and understand the culture of the minority population available. Minority population might be coming from countries where newborn hearing screening is not an option, and they might not be aware of EHDI programs and the importance of having their newborn tested. For these populations, it is really important to have somebody who can speak their language, telling them about the program, rather than just giving them written materials. There are good options to be implemented inside healthcare facility, such as bilingual minority healthcare providers, certified translators, and translation phone lines that the healthcare providers can use.

The fifth strategy is to collect EHDI data on race, ethnicity, and language spoken at home. Although this is a difficult task, it can be really useful to allocate resources and conduct research and test hypothesis that would benefit minority populations. For example, with this type of data it would be easier to find the causes of some disparities among minorities.

Our next strategy is to maximize the resources available within the community. For example: training parents of deaf children from different cultural backgrounds to serve as translators and guides that can help families to go through the EHDI system.

Some states already have programs like this, such as Wisconsin's Guide By Your Side program. Support groups for families that involve members from minority populations can also be an excellent resource for new families.

The last strategy is to determine the particular needs of the target population. The process of finding information and making decisions for minority families of children with hearing loss is really complex. Minority families often have to deal with additional issues such as how to communicate with their children in multiple languages. The languages could include ASL, English, and their own native language. These and other issues must be addressed when giving information to minority populations.

Those are the strategies that I have right now, but this is not a complete list of factors affecting EHDI minority population. Each state has its own concerns and should address these issues according to the needs and resources available within each state.

Jamie Elliott: Thank you, Claudia. I want to thank everybody, all of our speakers first of all for very interesting presentations today. And I want to apologize for the music that was on earlier. I hope it wasn't too distracting as our presenters gave their talks for us today.

If anyone does have questions for our speakers, please go ahead and ask now. No questions?? All right, then, thanks to everyone for joining us today.

The next teleconference will be in April, and we will send out transcripts for today's call in about two to three weeks.

Participants: Thank you. Thank you.
[End of call]

Edited Transcript – version 3